

# Vermont Developmental Disabilities Council 2006 Survey Comments

## Thoughts on Services and Supports for People with Developmental Disabilities in Vermont – Unmet Needs and Ideas for Change

179 Vermonters responded to the Vermont Developmental Disabilities Council's Survey to inform its revision of its 5 Year State Plan

The questionnaire was available online and in print in early 2006. Questions covered the general availability of information and funding, and asked how Vermont is doing in providing people with developmental disabilities services and supports in a number of areas such as employment, housing and education. For each, Vermonters were asked to rate how the state is doing on a scale of five possibilities, to comment further, and to suggest what needs to be improved. Responses were of varying lengths and depths.

Those who responded to the survey were asked to identify their involvement with disability issues. The options were

- Person with a developmental disability
- Person with another disability
- Family member of a child with a developmental disability
- Family member of an adult with a developmental disability
- Direct service provider
- Work for a non-profit/community or advocacy organization
- Work for a local or state government agency
- Volunteer member of a community or advocacy group
- Volunteer member of a public policy board
- Public policy maker
- Other

and those responding could check as many as applied to them. Many checked more than one. Some checked as many as seven.

The Council's mandate is to identify and then help to fix gaps in services. This compilation focuses on responses that seemed to me to identify and illuminate needs and problems – responses that could help us both expand and focus our thinking about what our 5-year plan should look like.

This compilation covers the written comments. Numerical responses are analyzed in other documents. They are presented in the order in which they appeared on the survey form. The selected responses are in the order their responses were entered into the data base – earliest responses first. Generally, only one area of involvement is identified for each person, with the involvement highest on the list. In part, this was done to preserve anonymity and privacy. All comments are the full comment made. No editorial comments are made by me. The general format is inspired by Rep. Jason Lorber's "53 Voices on Correction in Vermont" (December 19, 2005).

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## Comments on Information Available to People Seeking DD Services

**The state plan for DDAIL/DS cannot be allowed to ignore by "low priority" a whole portion of the population. We must find the resources to take care of each other! -**  
- State/Local Agency Employee

**Respite is so important; families burn-out with the demands of taking care of DD child. PCA allowed my daughter to be safe and working on goals for ADA and allowed me time to run the house: pay bills, do dishes and laundry, make dinner. She needs constant supervision... – Family Member of Child**

**There are waiting lists in my community for these services – Family Member of Child**

**Current intake process at designated agencies turns people away rather than assist them; "applicant list" doesn't reflect those who either don't bother to apply or are turned away at the threshold. – Family Member of Child**

**State requirement and funding are ridiculous. – Family Member of Adult**

**Inclusion is not working for all!!! Inclusion can lead to exclusion. – Family Member of Adult**

## What Needs to Be Improved to Provide Information About Needed DD Services and Supports

**Vermont needs a one-stop shop where families can receive ALL information available on special education, respite, personal care, summer camps, grants, etc., in addition to unbiased information on therapies, treatments and educational programs, whether or not they have years of research behind them. Parents are smart enough to read information and make their own decisions. Parents do not need a middle-man to screen the information before passing it along to parents. – Family Member of Child**

**There is no one place to go (that I have found anyway) to get information about what your child may be eligible for. People with very intensive needs may or may not be getting the services they are entitled to. My son has Autism. Every week, I learn from OTHER PARENTS what he may be eligible for. This state is small. We need an Autism Center, or a Developmental Disabilities Center with separate divisions, where ALL the resources are consolidated! It is a crime that we don't already have this in place. – Family Member of Child**

**AHS needs to be honest with people about what people are entitled to instead of making it a treasure hunt for who has the most perseverance. – Family Member of Child**

**I wrote sometimes because much of the information I have ever gotten has come through other parents in conversations versus from agencies or professionals.**

**There needs to be a complete list of available services in one publication that is user friendly.** – Family Member of Child

**Everything! Parents have to fight all the time for what their children need. Schools should be trained and held accountable for services.** – Family Member of Adult

**Communication. Often families need to know what to ask for, rather than being told upfront what they qualify for** – Family Member of Child

**I usually fall upon services available by chance or through word of mouth. I wish there were a database or other resource to see a menu of available services and supports with a brief description of how they support individuals with disabilities and their families.** – Family Member of Child

**Reliable, predictable respite is often hard to come by. There is no central bank of names, or database of when respite providers are usually available, what clients they are willing to provide for, etc.** – Direct Service Provider

**Information is not always forthcoming. People in the DD system have different information, some is accurate some is not.** – Family Member of Child

**Adult services to high IQ low functioning adults, need appropriate job supports** – Family Member of Adult

**Budgets keep getting cut so funds are limited to basic community services and not personal growth.** – Direct Service Provider

**New people graduating don't have funding. The only way is if they lie and say they'll be homeless.** – Person with a Developmental Disability

**i am always wondering what i do not know that may be out there for my young adult** – Family Member of Adult

**The system for providing families with respite support. It doesn't seem right that families are put on waiting lists that can last for longer than a year. From my understanding some families receive support and will always have this support while other families receive nothing.** – Direct Service Provider

### Comments on Funding for Needed Services and Supports

**The word between families who need services is hang on to what you get because even if you don't need it now but need it later you probably won't get it back so some funding is wasted simply because people are afraid they will lose it and then need it.** – Family Member of Child

**More flexibility within an existing waiver -- consumers should be able to use the funds for "approved" services as needed without having approval from DAIL ahead of time.** – Nonprofit Community/Advocacy Agency Employee.

**It seems every year for the last 5 years funding has been in jeopardy, even though the cost of living is ever increasing.** – Person with a Developmental Disability

**As part of an extended family of a 5 year old who needs a great deal of help with sensory issues, I've been disturbed by the lack of help available to a small family, struggling to survive.** – Family Member of Child

**Since 2001 children were dropped as a funding priority** -- State/Local Agency Employee

**Often it is funding that drives service availability, so the lack of services is often tied to inadequate funding for those services.** – Family Member of Child

**Squeaky wheel rather than neediest gets help.** – Family Member of Child

### What Needs to Be Improved on Funding for Needed Services and Supports?

**funding priorities eliminate some needed services for our families. funding lacks create holes in the system families are unable to fill.** – Family Member of Adult and Child

**Lots of people are left out of the funding loop for one reason or another** – Family Member of Child

**Funding has become more difficult for families and individuals to receive. Some have had an increase in needs, which is very easy to see yet they have been denied more funding to assist with those needs. This is very frustrating for Families, home providers and individuals.** – Nonprofit Community/Advocacy Agency Employee.

**Some of the funding my son receives is wasted because it goes through an agency and pays for services and case managing that he doesn't use.** – Family Member of Child

**If more money is spent on these kids when they were little, the state would not have to pay for so much into adulthood.** – Family Member of Child

**seems the piece of pie is getting smaller. howard community services making eligibility tougher because there is less funding. the transition age students who are aging out of state custody and don't fit spectrum's criteria because of cognitive deficits end up on the street, or in jail...sad sad sad** – Family Member of Adult

**System of Care plan applies only to those who have fallen through the cracks and is not used proactively to prevent the need for increased services later on in life.** – Nonprofit Community/Advocacy Agency Employee

**No money for children. Funding is crisis only. Families and teams are made to beg. No case management funds for PCS. Funding is very limited for adults. Cannot get more than 20 hours of funding for employment supports even though company will support increased hours and individual wants to work more. – Family Member of Child**

**Eligibility criteria has narrowed over the years, allowing fewer people to obtain needed, critical support services. This wastes the educational investment the state has made not to mention the individual's life and potential contribution. We need an entitlement to services and a new system of support...the current one is too costly and serves too few individuals. – Family Member of Adult**

**Why do I have to use my PCA as a summer aide for my daughter? I work in early intervention and state leadership at FIT is not knowledgeable about autism interventions, intensity, and the leadership delays services for birth-3 children with autism, seemingly deliberately, to save money. – Family Member of Child**

**while respite care is available to children, there is little funding available for other services and supports. Training for PCA's, funding for additional therapies, such as speech, additional ot etc is lacking. – Family Member of Child**

**DS needs to change their funding priorities so that they can serve kids. We know prevention works, yet DS has changed their funding priorities to exclude kids. Funding priorities are inconsistent with Best Practice. Forces kids to be served through other AHS agencies that do not have adequate expertise. Shifts cost to other AHS Departments. Also need to create more flexible funding so that it is not waiver (all) or not waiver (none). – Family Member of Child**

**More agency-funded programs so recipients can be more active and get learning programs. – Direct Service Provider**

**Services and supports to adults with less-common/less-understood developmental disabilities – Family Member of Adult**

**The emphasis is not as much on the need as much as it is on how much the state can afford. Funding priorities are shrinking every year due to budget restrictions. – Direct Service Provider**

**Access to funds for needed supports outside the current System of Care Priorities. More flexibility in the use of funds for self-managing Vermonters as long as the funds meet a disability-related need outlined in the person's ISA. – Nonprofit Community/Advocacy Agency Employee**

**After graduation from HS, the supports for work and community participation are difficult to get and keep -- Special Education Teacher**

**State equity is not providing funding for people who don't meet a priority. We should be funding them now to avoid a crisis (priority) later. We fund people who are a safety issue to themselves and community; these folks are dual diagnosed and DD is the least of the matter. They need psychiatric supports, not a DD program. Most of these consumers do not even want our services, but either the**

**legal system or their guardian feels they should. We fight them to provide services, meanwhile the consumer who wants help can't get it. – Direct Service Provider**

**Everything is about money now.....people with disabilities are not a priority in this state – Family Member of Child**

**Systems of care plan has been eviscerated and should be discarded. Needs to be more equitable distribution of resources, and less funding spend on agency overhead masked as "case management" using up more resources than direct services and supports for people. – Family Member of Child**

### **Comments on How Vermont is Doing in Providing Jobs and Employment Supports**

**Are there jobs in Vermont???????? – Direct Service Provider**

**The local agency has revamped their programs, but in general I have not heard that it has benefited the individuals with dd a great deal. – Nonprofit Community/Advocacy Agency Employee**

**There is very little imagination about what people can do; even high school kids are trained to do custodial or food service work. – Family Member of Child**

**Rutland industries was one of the few places that hire just physically or emotionally disabled persons. They had to lay off people due to lack of contracts to work for other companies. They were forced to lay off 2/3 of their employees. Only 1/5 of that found alternate employment. – Family Member of Child**

**There is more than cleaning that can be done. – Person with a Developmental Disability**

**My daughter has wanted a job since she was 16. The school did little to obtain even volunteer positions. Now as an adult, she has waited 8 months and no leads, even for a volunteer job. Where I work, I see many individuals with disabilities that are relegated to a lifetime of poverty trying to survive on SSI. They do not have enough money for food or to hope for a different life. – Family Member of Adult**

### **What Needs to Be Improved in Providing Jobs and Employment Supports?**

**There are no jobs for mentally disabled that pay a livable wage. No employment training resources – Nonprofit Community/Advocacy Agency Employee**

**The State has to provide necessary supports to people with developmental disabilities so they can work. The State has to establish true partnerships in the**

**private sector to hire people with disabilities and should be hiring people with disabilities too.** – Person with Another Disability

**More people need support. Some get excellent support, some fair, some really poor, and some none.** – Family Member of Adult

**I hear that outside of Burlington and Montpelier job supports aren't available. This is crucial. Adults with DDs need work for dignity and purpose.** – Family Member of Child

**Services for people who "fall between the cracks" with IQ too high for help, but abilities too low to find work.** – Family Member of Adult

**its hard to get enough hours- my daughter works 6 hours per week and it does not look like the organization can give her more hours** – Family Member of Adult

**From folks that have adult children with Autism I hear there are no real supports if adult is fairly high functioning. I don't know about other functioning offspring.** – Family Member of Child

**Community acceptance- We still encounter businesses saying "We don't hire your kind of people."** – Nonprofit Community/Advocacy Agency Employee

**I've been at my job for about 8 years and have not heard a lot of good things about employment opportunities for people with dd.** – Nonprofit Community/Advocacy Agency Employee

**People still do not work for fear of losing health care benefits and security of SSI & waivers; need to think more expansively about what kind of jobs people can do, especially in emerging "industries" People should not have to choose between employment and community support. Cap of 25 hours does not work.** – Family Member of Child

### Comments on How Vermont is Doing in Providing Community Supports for Recreation, Social and Leisure Activities

**Clients are with their families 24 - 7 and need to spend time with others.** – Family Member of Adult

**Not many people are aware of the issues if they don't have family members who are affected.** – Person with another Disability who is a Family Member of a Child and an Adult with DD

**I don't know much about that. I don't get enough information about community activities for my son** – Family Member of Child

**Most individuals and families I know of complain about no friends or lack of social life** – Family Member of Child



## What Needs to Be Improved in Providing Community Supports for Recreation, Social and Leisure Activities

**I think we need to look at being able to provide more supports in evenings and on weekends, when there are things going on in the community that are of interest to individuals that we support.** – Nonprofit Community/Advocacy Agency Employee

**Funding for community services and respite are not enough to meet individuals daily supervision needs.** – Family Member of Adult and Child

**This year my son is participating in the adaptive ski program at Sugarbush, which is excellent. I would be great to have more adaptive activities. Also activities that were SOCIAL would be good-- the ski program is good for skill building, but doesn't provide social opportunities really with other kids. A "circle of friends" type of program for after school and in the community would be awesome.** – Family Member of Child

**There needs to be more activities specifically geared to special needs. There is a group of profoundly disabled individuals who spend their whole life adapting to everything. There should be things created just for them and the rest of the community can adapt if they like.** – Family Member of Child

**Not enough coordinated supports in communities. Too much emphasis placed on what providers want not enough on listening to what individuals want.** – Family Member of Child

**We need more agency involvement and opportunities to support recreation and social events. The private sector is doing okay but the grant \$\$\$ are getting harder to come by. This topic doesn't seem to be a priority for state folks. As children grow older it is natural to look for opportunities out of the family setting and they can be difficult and not consistently offered.** – Family Member of Child

**Many children , particularly with autism or other significant disabilities, require support in home, school and community. We are working diligently to provide a comprehensive school program . We are challenged by the lack of support for the children in their home and community setting. Schools are being asked to provide more and more of that service for families. We do not have the resources to do so.** – Public School Supervisor

**i guess i will always be the planner of the social calendar for my daughter- i guess that is just the way it is** – Family Member of Adult

**In Southern Vt. there is little available to anyone, say nothing about people with developmental disabilities** – Family Member of Child

**The majority of individuals we serve do not have any access to community supports. They do not meet the system of care priorities and are served through an employment grant. This is incredibly important as individuals are extremely**

**isolated and often depressed as the only social opportunities they have are at work or with their employment consultants.** – Nonprofit Community/Advocacy Agency Employee

**No opportunities to participate in activities made available to all. I want general public exposure to people with dev. disabilities.** – Family Member of Child

**People with visible disabilities can be segregated in the middle of a group of people. Attitudes are slow to change in the general population. The way 1:1 support "presents" people in their care is very important and could use some ongoing education.** – School Special Ed Employee

**It seems that people don't do a real lot out side of agency work hours 8-5 PM M-F. Evenings and weekend people w/dd are mostly left alone. People with disabilities need to have real relationships with community members in order to participate. Someone needs to be charged with that task; to help create real relationships by making connections to community members that share the same likes and interest of the individual with dd.** – Nonprofit Community/Advocacy Agency Employee

**People should not have to choose between employment and community support. Cap of 25 hours does not work.** – Family Member of Child

### Comments on How Vermont is Doing in Providing Transportation to Hold Jobs and Participate in Social and Leisure Activities

**A "Medicaid ride system" should be in place for disabled to benefit mental health: social activities, training, skill enhancement, exercise programs** – Nonprofit Community/Advocacy Agency Employee

**As parents of these children age and can no longer transport their young adult these young adults in rural areas are forced to stay home or use limited funds for drivers. No jobs, no social life, no friends or support group - just TV - UGH!** – Family Member of Adult

### What Needs to Be Improved in Providing Transportation to Hold Jobs and Participate in Social and Leisure Activities

**No transportation available in small communities other than caregivers - cost of the vehicles can be prohibitive.** – Family Member of Adult

**There is a need for improved community transportation that is affordable and dependable across the state.** – Family Member of Child

**Transportation to and from remote areas does not exist. Many mentally disabled clients miss out on social experiences because of lack of transportation. – Nonprofit Community/Advocacy Agency Employee**

**In rural areas it is hard for people with disabilities to access jobs, because transportation is so limited. More funds and expanding criteria for rural community transportation would and could be helpful. – Family Member of Child**

**The Legislature and the Administration are not paying any attention to the needs of people with disabilities for transportation to anything other than medical appointments. More money is needed to provide good transportation services so people can visit family and friends, go to church and the movies, etc. – Person with another Disability**

**I have to plan my whole day, every day around what my child has to do that day. I have to work nights and transport during the day with little sleep. – Family Member of Child**

**Not all disabled people are in wheelchairs and if not it is very difficult to get them to work etc. if they live out of town. SSTA only goes so far – Family Member of Adult**

**ssta needs to screen their drivers for sexual predators, and to make sure that those driving the vans are appropriate. had a bad incident this summer about a driver. – Family Member of Adult**

**Since there is little to no social, leisure, job supports there is little to no travel support as well. – Family Member of Child**

**Brattleboro is bad enough in our area with some bus service, but what happens in rural surrounding towns with dirt roads and long distances? Answer - Nothing! – Family Member of Adult**

**Public transportation outside of larger cities is virtually unavailable. – Person with a Developmental Disability and Family Member of Child**

**SSTA is great about providing regular transportation for her-we live in Williston and she gets rides 5 days a week to and from Williston to Burlington- that is GREAT. – Family Member of Adult**

**If you live in rural areas which most folks do - transportation is expensive and most of the times not available. – Family Member of Adult**

**It is very difficult for parents of children birth to three with developmental delays to get their children places if they do not have a vehicle. Many children who desperately need social interactions, such as playgroups, are unable to attend due to lack of transportation. It would make an incredible difference for many children, if they were able to attend playgroups. – Direct Service Provider**

**I often hear about how transportation is generally not available (rural areas) or how funding has to be cut for this vital service component. – Family Member of Child**

### Comments on How Vermont is Doing in Providing Housing and Home Supports

**THE PEOPLE I HAVE DEALT WITH DO NOT BEGIN TO TREAT ME LIKE A HUMAN BEING – Family Member of Child**

**Being able to have his cat has made a big improvement in his life. Almost no landlord allows pets. They are very helpful to some people. – Family Member of Adult**

**A residential option is needed in VT. – Family Member of Child**

### What Needs to Be Improved in Providing Housing and Home Supports?

**Inconsistent and poor advertising for housing, and SLP's within the state and area. Not enough SLP or respite training and their feelings of "being left out" creates rumors that discourage and damage future hopefuls. Also the cost and benefits are low or none which also discourages folks from participating in becoming home/SLP. More funding to make wage and salary more competitive and realistic for what is being asked of the SLP or emergency respite providers. – Family Member of Adult**

**Very strongly feel this is a weak area. More housing needs to be made available for young adults. I am concerned for when my child becomes an adult that there will not be assisted living facilities available. – Family Member of Child**

**I'm checking not good-I don't know of any home supports, except PCA's. And PCA's are hard to find and there isn't any training available for them. – Family Member of Child**

**Safe and acceptable housing for DD persons is difficult to find. Developmental home providers are becoming harder to find with VT's aging population. – Family Member of Adult**

**So far my experience has been that our family has been provided a lot of support. I do wish that funding support was more flexible though. As a single mother I can think of other ways I need support than just respite. I also wish that parents could be paid respite for their own child if they chose to give up work to stay with the child. It can be difficult having so many inadequate people helping out with your child all the time. – Family Member of Child**

**With the cost of keeping home repaired, myself and my son both on SSI just barely make ends meet. – Person with a Developmental Disability**

**Lives at home with us but she would like to live on her own- will always need support.** – Family Member of Adult

**Not enough independent living options. If folks have willing parents it is assumed that this will be their living situation. With support, many young adults would like to move out liker their same-aged peers without a disability.** -- Special Education Teacher

**Stability. I'd like to see some options for a couple of people with disabilities to live together with some level of independence.** – Family Member of Child

**We need funded housing options for some "group" homes. Many of consumers benefit from slp's with no more than two consumers in the home. There are some consumers who for many reasons need a more structured setting to them and community safe. This option might also help agencies keep consumers from reoffending in different areas of law violation.** – Nonprofit Community/Advocacy Agency Employee

**All too often people with developmental disabilities are in the equivalent of adult foster care, euphemistically called "home providers", not treated as adults.** – Family Member of Child

### Comments on How Vermont is Doing in Providing Health Care and Related Supports

**AS ABOVE THE PEOPLE THAT I HAVE BEEN DEALING WITH DO NOT TREAT ME LIKE A HUMAN BEING** – Family Member of Child

### What Needs to Be Improved in Providing Health Care and Related Supports?

**The entire health care system in the US is run by pharmaceutical companies and their profits and so unsupportive of the people they are supposed to be serving that I cannot separate out individual needs of people with DD from the entire tragedy. We are all pawns.** – Family Member of Adult

**Personal care attendants need to receive a liveable wage and health insurance so that more people will see it as an employment option. People with disabilities need to be viewed as a whole person deserving of care and things like dentures and glasses not just minimum health care services.** – Person with another Disability

**I live in Chittended county where I feel insulted each time I hear Fletcher Allen referred to as a "Children's" hospital. It is a learning campus, yet they specifically exclude our children as they don't kow how to help them. That is what research and education is all about. For referrals and specialists, we are forced to leave the state to seek expert advice.** – Family Member of Child

**People who get too much SSD to qualify for Medicaid, but can't afford health insurance.** – Family Member of Adult

**Many families with Autism are turning to other states for expert medical care of their children.** – Family Member of Child

### Comments on How Vermont is Doing in Providing Early Intervention and Child Care

**Services are stretched so thin in rural areas like the Northeast Kingdom, that families aren't being served like they need and providers get burnt out.** – Family Member of Child

**The system seems to be very good for small children we had great success, it's as they get older that issues arise.** – Family Member of Child

**A Head Start visitor was instrumental in getting the disability diagnosed, but there seems to be nothing beyond diagnosis, like treatment, alternative education etc.** – Family Member of Child

**There has, however, been considerable improvement on issues of tolerance, acceptance, and bullying.** – Family Member of Child

**I'm not sure "what needs to be improved" but I know that improvements are needed because there are families that are not getting the services they need.** – Person Not Directly Involved

**Birth to 3 model of service coordinators that bridge medical, education & developmental services is great. My child with a disability could not attend a community based non-profits child care because we could not find an aide; neither school nor child care felt it had any obligation to help.** – Family Member of Child

**My two children were kicked out of a total of 8 daycares. They all claimed they needed too much one on one. There were limited funding and staff available so i was forced to stay home and quit my job.** – Family Member of Child

### What Needs to Be Improved in Providing Early Intervention and Child Care?

**More funding to support the growing demand for early intervention services. The need for more intervention at early ages is growing and the staff to adequately serve the families is limited. Especially in the Northeast Kingdom area.** – Family Member of Child

**Parent to Parent and FIT (Family, Infant, Toddler) do a phenomenal job of supporting the family prior and after diagnosis. However, when your child reaches 3 all these wonderful supports magically disappear. My childcare experience has been positive once intervention began, only because of parent to parent and having an amazing EEE teacher that came to work with them. – Family Member of Child**

**I work in this field( birth to 3 early intervention). We are doing ok with many children, but we are failing children with intensive needs. Field workers have to fight the system to get kids services. State leadership at FIT is uninformed about autism interventions, does not accept the need for intensive (25 hours/wk plus) intervention, and drags its feet to save money. It is extremely difficult to get an individual assistant for a child with extreme aggression or with autism. – Family Member of Child**

**Funding priorities do not allow for children to be served through DS. Need a more flexible funding that allows DS to better partner with other state agencies to develop services. DS waiver funding is all or nothing. – Family Member of Child**

**Services are provided when you know how to get them or if someone recommends them. – Family Member of Child**

**We need to reach out in communities to help children get services before reaching pre-school screenings. – Direct Service Provider**

**Children with developmental disabilities should be going to school for the amount of time that is needed for them to go to school. They don't get enough time for education. – Family Member of Adult**

**Pay scale for FITP personnel; FITP paperwork systems; coordination between SU's and FITP – Nonprofit Community/Advocacy Agency Employee**

**Maintaining a system that supports specialized intervention to those children who are part of low incidence populations. A generic model would not be the best choice for those children and families – Nonprofit Community/Advocacy Agency Employee**

**Our early intervention system does not provide adequate services for children with intensive needs. The 1 hour per week/month visit does not work for these children. – Family Member of Child**

### **Comments on How Vermont is Doing in Providing Special Education, Including Transition Services**

**I'M NOT SURE WHAT THE PROBLEM IS BUT I THINK THE PEOPLE IN THEIR POSITIONS HAVE BEEN THERE TOO LONG AS THEY SEEM TO HAVE FORGOTTEN THAT THEY ARE DEALING WITH REAL PEOPLE, REAL FAMILIES AND REAL HEARTBREAK – Family Member of Child**

**A large amount of a districts budget is spent on training Early Ed teachers, para's, etc., but then they drop the ball on how much they spend on K-12 training. If they are going to spend this much money to train Early Ed staff, then Early Ed staff should be required to move with the child to Kindergarten. More money needs to be spent on training K-12. – Family Member of Child**

**Falls down with increasing age. – Family Member of Adult**

**Make sure all children are meant to feel welcome. Special education is more than just the law. – Family Member of Child**

**My experience and research in programs across the state indicate a wide variability in the quality of services for students with significant developmental disabilities. This is being addressed at several levels. – Family Member of Child**

**Success stories are rare; crisis abounds. – Family Member of Child**

### **What Needs to Be Improved in Providing Special Education, Including Transition Services?**

**Most small schools do not have the initiative to design programs for our special children and little is done about transition except Voc Rehab. – Family Member of Adult**

**Transition services are often off people's radar, pushed aside, misunderstood. More education is needed in this area for all concerned. Special education services are mired in unnecessary paper work, and therefore focused on the unnecessary paper work, to the detriment of the actual education of the students. – Family Member of Adult**

**Devastating to move from Early Educaiton to Kindergarten. Early ed provides so many more supports than K. It is such a drastic transition for parents – Family Member of Child**

**Special education is a mess. The parent is put in charge of too much and often the quality of a child's programming seems to depend on the ability of the parent to be an advocate. Special education seems to vary widely from school to school. My son is not at the age where we would be planning for transition from high school yet, but I have heard lots of horror stories and am nervous about it. It seems a big part of the problem is not having good (or any, in some cases) programs (vocational and housing) to transition the kids to. – Family Member of Child**

**Special Ed is not consistent throughout the State. Parents have to advocate like crazy to get what their child needs. Its a fight, not a right at many schools. Transistional services are very poor at best. – Person with another Disability**



**It all depends on the school, the district, the teachers and other professionals. There has not been enough information provided to schools on how to adapt for inclusion. Special education is not treated as an equal like regular education. Not enough people understand the importance of it or care. Also inclusion the way Vermont is doing it promotes the segregation of disabled people. They are never together in school so they always have to adapt. We have gone from one extreme to the other. – Family Member of Child**

**Other than the fighting that parents have to do, teachers, and other staff are untrained, inexperienced and are getting away with pushing these kids through the system and out the door. – Family Member of Child**

**Teachers need to be more open to having these children in their classes and treat each one of them in an individual way. What works for one may not work or be best for another. Some do very well mainstreamed with support and some may not. – Family Member of Adult**

**Services across the board, especially related services for children with IEPs. Parents are exhausted and having to battle the system for every little detail is not a good method for attaining special education for their children. – Family Member of Child**

**Although transition planning is mandatory to the IEP process, it often occurs only sporadically, then is added to the IEP document, but ignored in practice. – Direct Service Provider**

**Money is such a big issue in the schools that it keeps coming up time and time again as a constraint to get needed services. Staff are not trained properly to work with these kids. – Family Member of Child**

**Uneven across the state. Transition to what? Right now it's a cliff for many. – Family Member of Adult**

**Schools and parents usually at odds with each other. Schools lack expertise in areas of disabilities. – Family Member of Child**

**Special ed is good but varies from school to school. Transition into adulthood is in BIG Trouble in VT as in it does not exist. – Family Member of Adult**

**Support from the powers that be (\$) to provide children with increased services when necessary for their educational program. – Direct Service Provider**

**Depends on the school --Children forced into a normal mold and have a hard time fitting in. – Person with a Developmental Disability and Family Member of Child**

**Support for families having trouble with school issues, extra services to supplement poor school services. – Family Member of Child**

**I would like to see a general curriculum for these kids, areas that need to be addressed, no matter what school you attend. – Family Member of Child**

**My son was forced to graduate without the skills needed to work or make change, purchase, or do routine math. English skills.** – Person with a Developmental Disability and Family Member of Child

**Schools need to be sensitive to the needs of special needs children, to make those children feel accepted and to provide services not only because they have to, but because it is the right thing to do.** – Family Member of Child

**Great struggle to get schools to provide even minimally adequate transition services to youths, supports to families working to achieve this for their youth is minimal.** – Person Otherwise Involved

**Reinstate finding for consumers age 18 to 19. The schools don't mind these children graduating but this leaves the consumer and families at risk for a year. Funding priority for June Grads is hard to meet as the need a job before agencies apply for funding (early spring) to be eligible. Services should be upped to have more graduates working should be looked at.** – Nonprofit Community/Advocacy Agency Employee

**Regionally dependent. The school I worked at last year was terrible, basically warehousing people with poor support. In my new job, things are much better.** – Special Educator

**Consistency across schools/location/programs is key, and does not currently exist.** – Family Member of Child

**There are no funds to pay for all the mandated services. Parents ask for them, sometimes they get put in an IEP, but there are not enough people in the school system to track, organize, specialize curriculum, and follow through the IEP for every student. More Federal funding? More teachers and aides? Better working TEAMS? Transition services to youth could include a complete career workshop; such that the individual gets to know what his/her interest and skills. Those ideas could generate a step toward creating a Circle of Support for the individual and making real community connections. Again, is the staff going to do it, can the family find the time? Will funding really solve the issue? Someone from the school system, the state system and the local system has to be appointed with this task. A transition is NOT, until real connections have been made.** – Nonprofit Community/Advocacy Agency Employee

**Stop babysitting kids with one-to-one paras who are not educators and calling it "mainstreaming" or inclusion. Stop patting our selves on the back on "inclusion" and look at the real social isolation that happens for kids, especially be high school. Don't sacrifice kids to philosophy! Needs to be a continuum of placements instead of being faced with sending our kids out of state. Would greatly benefit for Birth to 3 model of service coordinators that bridges medical, education & developmental services. Transition services for all who need them, rather than yearly dance at the legislature for funding. Prepare kids for meaningful, valued work . . . not just food service & custodial.** – Family Member of Child

**This varies depending on school district. Everyone talks the talk but not**

**everyone walks the walk.** – Family Member of Child

**Seems to be unclear what if anything CAP or VOC REHAB will or will not do until it is too close to graduation. Some of this is due to system of care that can decide for all to do nothing post graduate.** – Family Member of Adult

### Comments on How Vermont is Doing in Providing High-Quality Services and Supports and Ways to Evaluate Them

**Children have fallen through the cracks of the system even with parents advocating and trying to access as much services as they can.** – Family Member of Child

### What Needs to Be Improved in Providing High-Quality Services and Supports and Ways to Evaluate Them? Comments on How Vermont is Doing in Providing Individualized Services

**Limited budgets for programs and provider wages are limiting this. High rates of staff turnover is hurting this area.** – Family Member of Adult

**More funding to monitor and add employees so that people aren't trying to serve 20 families in a variety of ways.** – Family Member of Child

**There are tons of forms and questionnaires coming our way but they don't seem to change anything.** – Family Member of Child

**We are spending too much time and money on this and it is a very subjective process where people review services not knowing the consumer. How can you really find out if someone's services are of good quality if you only see them once every three years?** – Family Member of Child

**Not enough accountability from designated agencies.** – Nonprofit Community/Advocacy Agency Employee

**The best and often most cost effective help not available. Locked into strict categories. You don't fit the mold - tough. Quality testing not available to adults. My son's provider used an unqualified tester which disqualified my son for services. We later had a licenced and fully qualified professional evaluation at our expense which totally debunked the provider's expert and our professional backed up their findings with actual standardized test results but that doesn't matter. The tester the provider used was later in big trouble with the law but we are stuck with his results.** – Family Member of Adult

**I've had a son with special needs "in the system" for 15 years and never really been asked to give input in a quality assurance way. The system is not in place to get input and feedback directly from parents and consumers. The IEP goal achievements do not capture my feedback as a parent. No state agency we've worked with has actively sought out my opinion either. – Family Member of Child**

**I think our school needs to put in place more specific and scientific data collection for quality measures. We're relying too much on anecdotal evidence right now. – Family Member of Adult and Child**

**Quality Assurance needs to be improved and needs to be implemented in all areas. There is no program out there asking me how my child is doing now that she has graduated. – Family Member of Adult**

**Bodies such as the DD Council and the SILC need more authority. – Person with a Developmental Disability and Family Member of Child**

**QA is not very apparent. If services and supports are not adequate, what is done about it? – Family Member of Adult**

**I do not believe that our quality assurance systems get an accurate view of the state of affairs. – Family Member of Child**

**I am not convinced that the Consumer Survey done by the state is reflective of what I hear from parents and individuals. Perhaps the surveys can be done in a community setting, not at an agency. Not done on state of VT letter head? When there is connection back to the people who give you food, why would you say something bad about them, you want them to like and feed you. I believe that connection to some degree is being made when people w/dd fill out the survey. – Nonprofit Community/Advocacy Agency Employee**

**Designated agency services, from top to bottom. Direct support work force needs job security, benefits, and to be valued for quality to improve -- both at education and developmental services. \*\* Needs to be independent evaluation of the developmental service delivery system, with independent monitoring of placements. – Family Member of Child**

### **Comments on How Vermont is Doing in Providing Individualized Services?**

**Its difficult to answer this question for kids, as parents, are frustrated by DS funding priorities that excludes kids. – Family Member of Child**

**Agencies able to put unreasonable requirements on respite service providers which causes less availability of providers. – Family Member of Adult**

**Choices are good. Frequency is weak. – Person with a Developmental Disability and Family Member of Child**

**Afterall, as parents many of us with dev. disabled children are tired and stressed out. – Family Member of Child**

**VT gives the illusion of individual budgets. In reality almost 20% comes off the top they don't have access to, and often another 30% for service coordination that does not directly benefit the individual. Line items are very restrictive. – Family Member of Child**

### **What Needs to Be Improved in Providing Individualized Services?**

**Choice is always a problem and dependent on many factors. The irony is we have the right to choose but not from a wide selection. – Family Member of Adult**

**Limited budgets for programs and provider wages are limiting this. High rates of staff turnover is hurting this area. – Family Member of Adult**

**Limitations are due to the high need and limited resources and number of people that are available to give the service. Limited funding thus lower amount of employees, thus longer waiting lists. – Family Member of Child**

**Not sure what this question means. It isn't a question of CHOICE-- it is that there are not enough services. – Family Member of Child**

**It's good but there are so many unique situations out there. I think there still needs to be more flexibility. Parents are often giving up income and choices to care for their special children and there is no compensation for them to do so simply because they are the parent. – Family Member of Child**

**Don't know initially where to find them, when you find them you can't always access them, and there are not many in Vermont for people with autism. – Family Member of Child**

**Not a good variety of services, its a have to take what you are offered deal. – Family Member of Child**

**There isn't any choice in our (good) school system. It's take it or leave it or sue. – Family Member of Child**

**iep's are all over the place but are rarely followed as they should be and schools very often bypass parents or don't ask for their opinions. – Person with Another Disability and Family Member of Child and Adult**

**Client has care manager but caseload is so heavy sees them only once a month. – Person with a Developmental Disability and Family Member of Child**

**The business of resources is focused on referrals who refer. ie: state says "let me give you the name and number of someone who can refer you to some support services. No central database or one on one help to access services. – Family Member of Child**

**Regardless to what the teachers, administration etc. think, parents know there kids better than anyone, but it still comes down to money and getting the support people right for the job. It is all good to say a child needs PT 3 times a week, but when the money isn't there and a the PT people can only come 1x a month and they have to train an aide to do it and she is out or leaves, PT is down the drain and parents aren't always told they aren't getting it. – Family Member of Adult**

**Children usually are forced to fit into already existing services as opposed to having anything individualized for them. – Family Member of Child**

**You can't have individualized supports, if you don't know the individual! An ISA should not be drawn up until some sort of "Who Am I" worksheet has been done, so that the individual him/herself begins to know who they are, what they like, what they can do for skills, and what they don't like to do, what their interests are, etc. Only then can we have individualized services. – Nonprofit Community/Advocacy Agency Employee**

**More individual control of budgets, and making it easier to self-manage. More of waiver budgets going to direct services and supports chosen by the individual as less to thinly disguised overhead for the agencies in the form of "case management." More plain English information to participants in developmental services. – Family Member of Child**

**Choice of services is almost non-existent. People have to wait and unreasonable amount of time to get services and then they are often totally inadequate. – Family Member of Child**

### Comments on How Vermont is Doing in Providing Education About Civil Rights and Self-Advocacy

**Need simplification of information and resources need to be available to assist families and individuals if these rights are being violated. – Family Member of Adult**

**I'm not sure that everyone that receives services understands their civil rights. – Person Otherwise Involved**

### What Needs to Be Improved in Providing Education About Civil Rights and Self-Advocacy?

**As one of the advisors for our local self advocacy group, I speak from experience when I say that I it is difficult to be the best advisor that I can be and promote advocacy within our agency when advocacy is not my sole responsibility. I feel that HCRS would benefit from having one person whose was responsible for coordinating self-advocacy meetings, trainings, community events, etc. and who didn't have additional responsibilities of case management, etc. Our local group has received a lot of support from our administration, but I would like to see them**

**go this one step further. We meet regularly and try to get the word out about meetings.** – Nonprofit Community/Advocacy Agency Employee

**If you a person with a disability and are not affiliated with a community mental health agency, you are NOT included in civil rights or self-advocacy opportunities.**  
– Family Member of Adult

**I have learned to advocate for my son by educating myself and attending support groups.** – Family Member of Child

**More early advocacy, dedicated advocates before the clients reach 18 and schools tell them they do not need to listen to parents or have them in meetings.** – Person with a Developmental Disability and Family Member of Child

**Schools and mental health agencies ask what they can do for you? Not this is the range of services we can provided are you interested. No one tells you what is out there.** – Family Member of Child

**The supports are available, but an understanding of what constitutes a claim for services is not clearly understood.** – Family Member of Child

**Client & Parent support for legal services related to program/service decisions and eligibility.** – Direct Service Provider

### Comments on How Vermont is Doing in Advancing the Rights of Those With DD

**I went to my town hall to get a larger print ballot for my daughter this last November. No one knew what to do, what she was entitled to.** – Family Member of Child

**I think we are good about showing off our "model" DD population, but I'm worried about those we don't see in public.** – Family Member of Child

**Not every person is the same. Let them all be themselves.** – Family Member of Adult

### What Needs to Be Improved in Advancing the Rights of Those With DD?

**More GOOD homes for these people if they can no longer remain with their families - they cannot speak for themselves - someone needs to.** – Family Member of Adult

**As much as we want to believe that this doesn't happen much anymore, the DS community is still exploited. Again, more involved education to the community would be an improvement in itself.** – Family Member of Adult and Child

**Adult protection services do a good job of looking at complaints. I find them fair people.** – Family Member of Child

**The system needs to go back to the first draft of the System of Care Plan, where it really cared about the quality of life. The cut backs have made it crisis only, and that is NOT advancing.** – Nonprofit Community/Advocacy Agency Employee

**More oversight, for example adult protective services investigators; independent monitoring of developmental services.** – Family Member of Child

**Overall, many groups are okay with inclusion, but it's still hard to support persons with DD and parents are tired and want a life of their own by the time the person is an adult!** – Family Member of Adult

**People can advocate until they're blue in the face. Abuse is condoned in Vermont for people with disabilities. Even the DLP states this and are appalled.** – Family Member of Child

**Raise awareness of Police Departments about individuals with communication differences. They are seen as such poor witnesses, because they process language slowly, that their cases are often not pursued. My daughter was sexually assaulted, and in essence, no one was held accountable.** – Family Member of Adult

### Comments on How Vermont is Doing Overall, Locally and State-wide, in Reaching Out to Those With DD

**I believe Vermont does the best job that they can with the resources available. Compared to other states that I have worked in, Vermont far surpasses them in the delivery of services that are individualized to people's wants, needs, and interests.** – Nonprofit Community/Advocacy Agency Employee

**No attempt made to reach adults who had disabilities before age 22 but who were not diagnosed by age 22 because the state did not recognise most disabilities before special education law of 1976. Now these adults are stuck without proper services.** – Family Member of Adult

**Too many students with special needs are being stressed and not served appropriately.** – Family Member of Child

**There are some amazing success stories out there. Inclusion is something that consciously needs to be sponsored and acknowledged on an ongoing basis. Schools have an important role to play in modeling inclusion. Schools are the breeding grounds for our next generation of providers.** – Family Member of Child

**If you don't live in a more urban setting in the state, there is very little to do anyway.** – Family Member of Child



**My children are excluded from most recreation, social, and community life. They are excluded from classrooms and have very little social interactions. – Family Member of Child**

**What Needs to Be Improved in How Vermont is Doing Overall, Locally and State-wide, in Reaching Out to Those With DD?**

**I would say that Vermont has come a long way in these areas, however, again there is always room for improvement and I strongly believe that change happens through education. It's important for the DS community to bond with our communities and it doesn't happen if they are not a part of that puzzle. Education is the key to solutions. Hold community events and forums that provide the education, free to the public, by our consumers even. – Family Member of Adult and Child**

**From my experience, I would say not good in that there are very limited opportunities. – Family Member of Child**

**I'd say better than okay, but maybe not very good. – Family Member of Child**

**Very poor with children. Everyone thinks schools should have all responsibility for children. People need to learn that it is home, school and community that is needed. This is created by too little money and too many requests for funding. – Family Member of Child**

**Raising a child with disabilities is like going through a dark tunnel feeling your way through finding bits of information at a time. – Family Member of Child**

**I think we are better than other states, but that isn't saying much. Socialization is the key. More needs to be done to help families feel less isolated. – Family Member of Child**

**I don't know of the state as having a program that includes people w/dd in aspects of community life. Perhaps I have a different meaning of community life. But at the grocery store, gymnastics, cub scouts, girl scouts, dance company, city recreation sports, I don't see many people w/dd. That needs to be improved. The people providing day supports have to be responsible for night and weekends too, so they could be making real community connections for the individual w/dd to other people in their community that have the same likes, interests and abilities/skills. The state and local programs should be fostering a Circle of Support for all their individuals. – Nonprofit Community/Advocacy Agency Employee**

**How did I get to be 54 years old and know so little? – Nonprofit Community/Advocacy Agency Employee**

**We must resist the tendency to relax. There are too many people asking the question "do we need to be the best!" My response would be yes. But apparently there are some people who think otherwise. – Family Member of Child**

## Other Comments

**Parents work hard and complain little but caring for these children and adults can be exhausting. Perhaps if more services were available within the home, children/youth/adults could stay with their families. Imagine if your recurring dream is just one night of sleep without interruptions - it isn't asking for much is it? – Family Member of Adult**

**IT SEEMS THAT THE PEOPLE AT THE STATE LEVEL ARE ONLY LOOKING AT ONE WAY OF DOING THINGS WHICH DOESN'T WORK FOR EVERY PERSON. I THINK THAT THERE IS A LOT OF WORK TO BE DONE AND WOULD LOVE TO TALK WITH SOMEONE MORE ABOUT HOW I HAVE BEEN TREATED – Family Member of Child**

**We know that Vermont government wants to do what is best for those with special needs, but they may not be getting a clear picture of the problems parents face and the struggles they go through on a daily basis with their school districts. Thank you for asking for our input. – Family Member of Child**

**1 in 166 children are being diagnosed with Autism-this state has very limited resources to deal with that, and what we do have is scattered and families have trouble accessing it. It needs to be more centralized-we need an Autism Center!!! – Family Member of Child**

**Funding needs to increase for programs supporting individuals with disabilities, both at early ages and into the older ages. More staff needs to be hired in order to allow a decrease in waiting lists or programs having 4 year waiting lists for services to even begin. More funding available to assist programs in helping with grants to accommodate people with disabilities. – Family Member of Child**

**I want the council to understand how hard it is to go to work every day and have to make choices that cost family income to keep your special child well cared for and safe. The only people who can not be paid to care for a special child is the parent and that is wrong because they are the ones who are usually losing income and job time because of the situation. The "above and beyond" care of a special child changes everything and even more so for single parents. With the care giver shortage Vermont and the country need to support families to be the caregivers of the special needs children. Why do you keep finding ways to hire strangers when you could support the best caregiver of all, the parent. I have seen families break apart because of this or give up the child simply because the parent can not be paid to be the provider. It makes no sense. Vermont will spend a ton of money helping parents with special needs kids find other jobs while paying someone else to care for their child. Think about it. I am a parent of a special needs child, my own child's paraeducator, an LPN who cares for special children in their homes, and a respite provider. The state will pay me to take care of other children while they pay someone to care for my child. I dream of being able to work one job and care for my own children and still make ends meet. I am not alone in this dream. It doesn't have to cost the state more. Respite should be flexible for respite or family**

**support for the family choosing to care for the child and be supported. – Family Member of Child**

**My child fits the federal definition of DD, but not the State. Why doesn't the state adopt the federal definition?? – Family Member of Child**

**New teachers coming in that are not certified in Special Ed. but are on provisional licenses need to be mentored very closely. It caused great problems with my daughter in the beginning of the school year because I was unfortunate to have such a case manager!!! I switched to a case manager who has 10 years behind her-what a difference. Please look at these provisional licenses more closely-its affecting our kids!!!!!! – Family Member of Child**

**The council needs to go out to meet the people receiving services rather than waiting for people to come to them. – Nonprofit Community/Advocacy Agency Employee**

**This is an excellent survey. Good job. I would like to see the DD Council become more involved in advocating for individuals through testimony at the legislature, talking more to state officials and moving the meetings and community forums around the state. Very few people really know about what you do. Lots of people in the DD community don't even know you exist. – Family Member of Child**

**We need more money coming into this state for Autism. We need more people trained to work with these individuals and there needs to be a place that hires and trains people and pays them a decent wage. If you find a PCA on your own, they get paid \$10/hr. If the organization hires them than they get paid only \$8.50. Considering the challenges that these people face and not having any benefits such as dental or health they pay should be higher. Many of these kids can be aggressive and could hurt the PCA in their fits and that should be taken into consideration. – Family Member of Child**

**There are few if any services for high IQ low functioning adults with co-occurring disorders of autism/asperger syndrome-ADHD-mental illness. – Family Member of Adult**

**Other nearby states have several centers throughout their state that offer services for kids on the spectrum. Vermont does not even offer one. There needs to be at least one location that families can go to for needed support. By this, I mean that if the center does not offer services directly, it should at least be a resource for families of; what therapies are out there, who provides them, where to find quality PCAs & respite, support groups, counseling, etc. I would personally be happy to quit my job and be a part of creating a center in Chittenden County for families that are just starting out on this long journey. I would be happy to be the resource that I wish I'd had. – Family Member of Child**

**As with most all things, budget cut backs hurt those people who need the funds the most. – Person with Another Disability and Family Member of Child**

**I think the overall lack of available qualified / trained people to provide direct services such as respite and PCA work really impacts how the person is**

**integrated into their community. The lack of coordination of services also concerns me because this can lead to: needs not being met, duplication of services; confusion for families. – Direct Service Provider**

**I think people don't understand what definition you're using of "developmental disability" because most people think of the state definition of IQ below 70. My partner, who fits the federal definition (I think) does not get any supports or services, doesn't know about them, probably wouldn't feel comfortable approaching those she knows about because they appear to serve only a limited selection of individuals with developmental disabilities. (But where does mental health fit in? If the limitations are partially due to chronic mental health disorders and also due to learning disabilities and physical problems, where does that person fit?) – Family Member of Adult**

**It is extremely hard to find qualified staff to provide services for challenging children. If the school is also having problems with the child, then you have families left alone to deal with extremely difficult situations with no break in sight and with no support from any provider. – Family Member of Child**

**If funding doesn't increase to be able to address these issues, there is no point wasting your time discussing them. Adequate services in all areas cannot be provided without improved funding. My goal is to be able to continue to work while my daughter receives adequate service so she can work in a supervised safe setting to the best of her ability. – Family Member of Adult**

**The state and all of the decision makers need to keep their eye on the prize which is quality of life for people with disabilities. The Homestead tax issue is going to cost the state if they don't go back to what had been working. The reduction in Community supports to save money is another issue that will have a ripple effect on quality of services. – Direct Service Provider**

**I would like to see community adult homes like assisted living areas for the adults. Some one on duty 24/7 to assist as needed and continue the education processes for them. – Family Member of Adult**

**When you become a home provider they should tell you about all the money you have a right to. I had my persons for 10 years before anyone told me about home provider pay. I kept him for 12 years on only room and board. – Direct Service Provider**

**If you want to get some information, learn a new course, enjoy a movie, take a hike, go camping, have a cocktail, talk about things of interest, talk about financials, talk about relationships; how many people do you have to choose from within your Circle of Support? One, Two? No, and neither should people w/dd have only a few people to share their lives with, they should have as huge of a Circle of Support as they desire. Please take a project up on creating Circles of Supports. These comments are only my perspective of what I've seen and heard and thence concluded. Someone else may have a different truth! Namaste~ – Nonprofit Community/Advocacy Agency Employee**

**Let's face the INCLUSION DELUSION or ILLSION. People are still very isolated. Living with another family "home provider" does not decrease that isolation. Being "mainstreamed" with "peers" who never ask you out or over does not decrease that isolation. People need to stop patting themselves on the back about how much better it is here and look at reality. – Family Member of Child**

**Most social outings and events are unavailable to challenged adults after leaving high school. There is a huge need to get these adults out of the house for socialization as well as residential living arrangements. – Family Member of Adult**

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